

General

Title

Epilepsy: percentage of all patients with a diagnosis of epilepsy with active anti-seizure therapy side effects for whom an intervention was discussed.

Source(s)

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Process

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the percentage of all patients with a diagnosis of epilepsy with active anti-seizure therapy side effects for whom an intervention was discussed.

Rationale

Anti-seizure medications commonly cause neurological side effects such as sleepiness, dizziness, fatigue, and diplopia (Andrew et al., 2012). Some anti-seizure medications can cause idiosyncratic side effects such as weight changes, irritability or gastrointestinal issues. Patients must be queried about any general side effects and the side effects that accompany their specific therapy. Querying about side effects is perhaps the most straightforward, simple, and efficient intervention that could be provided to improve epilepsy care and patient engagement. Commonly these side effects can lead to decreased adherence thus increasing risk for further complications in epilepsy care.

The following clinical recommendation statements are quoted verbatim from the referenced clinical guidelines and represent the evidence base for the measure:

- When a patient with epilepsy receives follow-up care, then an estimate of the number of seizures since the last visit and an assessment of drug side-effects should be documented (Pugh et al., 2007).
- Patients with epilepsy should receive an annual review of information including topics such as: chronic effects of epilepsy and its treatment including drug side-effects, drug-drug interactions, effect on bone health (Pugh et al., 2007).
- Children, young people and adults with epilepsy and their families and/or carers should be given, and have access to sources of, information about (where appropriate): ... medication and side effects (Andrew et al., 2012).
- Treatment should be reviewed at regular intervals to ensure that children, young people and adults with epilepsy are not maintained for long periods on treatment that is ineffective or poorly tolerated and that concordance with prescribed medication is maintained (National Institute for Health and Clinical Excellence [NICE], 2012).
- Annual review should include an enquiry about side effects and a discussion of the treatment plan to ensure concordance and adherence to medication (NICE, 2012).

Opportunity for Improvement

A gap in care continues to exist with regard to querying about anti-seizure medication side effects as shown in some studies designed to determine the rate of compliance with the 2009 epilepsy quality measure (Fountain et al., 2011; Wicks & Fountain, 2012; Wasade et al., 2012; Cisneros-Franco et al., 2013; Fitzsimons et al., 2013). Using a standardized quality measure check list without any other intervention improved performance (Cisneros-Franco et al., 2013). Additionally, a recent review concluded, "questioning every patient at every visit to elicit information may be helpful when balancing benefit-to-risk of individualized therapy during everyday practice" (Cramer, 2012).

Further, if therapy adherence improves, there is a likelihood that costs of care would decrease, as anti-seizure medication nonadherence has been correlated with greater risk of hospital admissions, emergency department visits, head injuries, and fractures (Goodman et al., 2012).

Evidence for Rationale

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

Andrew T, Milin K, Baker G, Wiesmann U. Self-reported adverse effects of mono and polytherapy for epilepsy. *Seizure*. 2012 Oct;21(8):610-3. [PubMed](#)

Cisneros-Franco JM, Díaz-Torres MA, Rodríguez-Castañeda JB, Martínez-Silva A, Gutiérrez-Herrera MA, San-Juan D. Impact of the implementation of the AAN epilepsy quality measures on the medical records in a university hospital. *BMC Neurol*. 2013;13:112. [PubMed](#)

Cramer JA. Tolerability of antiepileptic drugs: can we determine differences?. *Epilepsy Behav*. 2012 Mar;23(3):187-92. [PubMed](#)

Fitzsimons M, Dunleavy B, O'Byrne P, Dunne M, Grimson J, Kalra D, Normand C, Delanty N. Assessing the quality of epilepsy care with an electronic patient record. *Seizure*. 2013 Oct;22(8):604-10. [PubMed](#)

Fountain NB, Van Ness PC, Swain-Eng R, Tom S, Bever CT Jr, American Academy of Neurology Epilepsy Measure Development Panel and the American. Quality improvement in neurology: AAN epilepsy quality measures: Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology. *Neurology*. 2011 Jan 4;76(1):94-9. [PubMed](#)

Goodman MJ, Durkin M, Forlenza J, Ye X, Brixner DI. Assessing adherence-based quality measures in epilepsy. *Int J Qual Health Care*. 2012 Jun;24(3):293-300. [PubMed](#)

National Institute for Health and Clinical Excellence (NICE). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jan. 117 p. (Clinical guideline; no. 137).

Pugh MJ, Berlowitz DR, Montouris G, Bokhour B, Cramer JA, Bohm V, Bollinger M, Helmers S, Ettinger A, Meador KJ, Fountain N, Boggs

J, Tatum WO 4th, Knoefel J, Harden C, Mattson RH, Kazis L. What constitutes high quality of care for adults with epilepsy. *Neurology*. 2007 Nov 20;69(21):2020-7. [40 references] [PubMed](#)

Wasade VS, Spanaki M, Iyengar R, Barkley GL, Schultz L. AAN Epilepsy Quality Measures in clinical practice: a survey of neurologists. *Epilepsy Behav*. 2012 Aug;24(4):468-73. [PubMed](#)

Wicks P, Fountain NB. Patient assessment of physician performance of epilepsy quality-of-care measures. *Neurol Clin Pract*. 2012 Dec;2(4):335-42. [PubMed](#)

Primary Health Components

Epilepsy; anti-seizure therapy side effects; intervention

Denominator Description

All visits for patients with a diagnosis of epilepsy actively receiving anti-seizure therapy with a side effect noted at time of visit (see the related "Denominator Inclusions/Exclusions" field)

Numerator Description

Patients with anti-seizure therapy side effects for whom an intervention was discussed (see the related "Numerator Inclusions/Exclusions" field)

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Importance of Topic

Epilepsy data is lacking. In 2012, the Institute of Medicine released *Epilepsy across the Spectrum: Promoting Health and Understanding*, detailing epilepsy research disparities and highlighting specific areas where further research is needed, including the extent of epilepsy, consequences, comorbid conditions and outcomes of epilepsy (England et al., 2012). The following statistics only touch on the magnitude of epilepsy given lack of research and stigma:

- It is estimated 2.2 million people in the United States are diagnosed with epilepsy, and 150,000 new cases of epilepsy are diagnosed in the United States annually (England et al., 2012).
- Epilepsy prevalence might be underestimated because of underreporting associated with repercussions and stigma in disclosing epilepsy (Kobau et al., 2012).
- Common comorbidities among people with epilepsy include somatic (i.e., fractures, asthma, diabetes, and heart disease), neurological (i.e., stroke, Alzheimer's disease, autism spectrum disorders, chronic pain), and mental health conditions (i.e., mood disorders, attention deficit hyperactivity disorders, anxiety disorders, suicidality) (England et al., 2012; Kobau et al., 2008).
- It is estimated the number of people with epilepsy who die of sudden unexpected death in epilepsy (SUDEP) range from 1 of every 10,000 who are newly diagnosed to 9 of every 1,000 candidates for epilepsy surgery (England et al., 2012).
- People with epilepsy are more likely to be unemployed or unable to work, have low annual household incomes, be obese and physically

inactive, and to smoke (England et al., 2012; Kobau et al., 2008).

- People with epilepsy have poorer overall health status, impaired intellectual and physical functioning, a greater risk for accidents and injuries, and negative side effects from seizure medications (Fountain et al., 2011; England et al., 2012; Kobau et al., 2008).
- It is estimated the annual direct medical cost of epilepsy in the United States is \$9.6 billion. This estimate does not include community service costs or indirect costs from losses in quality of life and productivity (England et al., 2012).

Opportunities for Improvement

Additional data on opportunities for improvement and gaps in care specific to the epilepsy measures can be located in the updated epilepsy measures.

- A review of 261 patient responses using the PatientsLikeMe survey system indicated a gap remains between recommended care detailed in the 2009 epilepsy measurement set and the care delivered to patients with epilepsy (Wicks & Fountain, 2012).
- The Institute of Medicine noted several gaps in care and opportunities for improvement, including 1) timely referrals and access to treatments, 2) epilepsy care and prevention, 3) education of persons with epilepsy and their families, and 4) the stigma of epilepsy (England et al., 2012).
- Surgery continues to be heavily underutilized as a treatment for epilepsy, with significant disparities by race and insurance coverage (Englot et al., 2012).

Evidence for Additional Information Supporting Need for the Measure

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: promoting health and understanding. 1st ed. Washington (DC): The National Academies Press; 2012.

Englot DJ, Ouyang D, Garcia PA, Barbaro NM, Chang EF. Epilepsy surgery trends in the United States, 1990-2008. *Neurology*. 2012 Apr 17;78(16):1200-6. [PubMed](#)

Fountain NB, Van Ness PC, Swain-Eng R, Tonn S, Bever CT Jr, American Academy of Neurology Epilepsy Measure Development Panel and the American. Quality improvement in neurology: AAN epilepsy quality measures: Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology. *Neurology*. 2011 Jan 4;76(1):94-9. [PubMed](#)

Kobau R, Luo YH, Zack MM, et al. Epilepsy in adults and access to care--United States, 2010. *MMWR Morb Mortal Wkly Rep*. 2012 Nov 16;61(45):909-13. [PubMed](#)

Kobau R, Zahran H, Thurman DJ, Zack MM, Henry TR, Schachter SC, Price PH, Centers for Disease Control and Prevention (CDC). Epilepsy surveillance among adults--19 States, Behavioral Risk Factor Surveillance System, 2005. *Morb Mortal Wkly Rep Surveill Summ*. 2008 Aug 8;57(6):1-20. [PubMed](#)

Wicks P, Fountain NB. Patient assessment of physician performance of epilepsy quality-of-care measures. *Neurol Clin Pract*. 2012 Dec;2(4):335-42. [PubMed](#)

Extent of Measure Testing

The new epilepsy measures are being made available without any prior testing. The American Academy of Neurology encourages testing of this measurement set for feasibility and reliability by organizations or individuals positioned to do so.

Evidence for Extent of Measure Testing

State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Ambulatory/Office-based Care

Hospital Inpatient

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Individual Clinicians or Public Health Professionals

Statement of Acceptable Minimum Sample Size

Does not apply to this measure

Target Population Age

Unspecified

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

National Quality Strategy Priority

Person- and Family-centered Care

Prevention and Treatment of Leading Causes of Mortality

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Data Collection for the Measure

Case Finding Period

Unspecified

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Clinical Condition

Encounter

Therapeutic Intervention

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions

All visits for patients with a diagnosis of epilepsy actively receiving anti-seizure therapy with a side effect noted at time of visit

Note: Refer to the original measure documentation for International Classification of Diseases, Ninth Revision (ICD-9), International Classification of Diseases, Tenth Revision (ICD-10), and Current Procedural Terminology (CPT) Evaluation and Management (E/M) service codes.

Exclusions
Unspecified

Exceptions
Patient or caregiver declines to answer questions on anti-seizure medication side effects.

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions
Patients with anti-seizure therapy side effects for whom an intervention* was discussed

**Intervention:* Discussion about significance of side effect symptom and consideration of adjustment in anti-seizure therapy or medication dose or providing alleviating treatment.

Exclusions
Unspecified

Numerator Search Strategy

Fixed time period or point in time

Data Source

Electronic health/medical record

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Unspecified

Computation of the Measure

Measure Specifies Disaggregation

Does not apply to this measure

Scoring

Rate/Proportion

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

Measure #3: querying and intervention for side effects of anti-seizure therapy.

Measure Collection Name

Epilepsy Quality Measurement Set

Submitter

American Academy of Neurology - Medical Specialty Society

Developer

American Academy of Neurology - Medical Specialty Society

Funding Source(s)

American Academy of Neurology

Composition of the Group that Developed the Measure

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American Clinical Neurophysiology Society: Susan T. Herman, MD

American College of Emergency Physicians: J. Stephen Huff, MD

American Epilepsy Society: Gabriel U. Martz, MD

American Society of Neuroradiology/American College of Radiology: Marvin Nelson, MD

Child Neurology Society: Inna Hughes, MD, PhD

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Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

Endorser

American Epilepsy Society - Medical Specialty Society

Child Neurology Society - Medical Specialty Society

Epilepsy Foundation - Medical Specialty Society

Date of Endorsement

American Epilepsy Society: 2013 Jul 29

Child Neurology Society: 2014 Jul 29

Epilepsy Foundation: 2014 Aug 7

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2014 Jan

Measure Maintenance

Unspecified

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

Measure Availability

Source available from the [American Academy of Neurology \(AAN\) Web site](#) .

For more information, contact AAN at 201 Chicago Avenue, Minneapolis, MN 55415; Phone: 800-879-1960; Fax: 612-454-2746; Web site: [www.aan.com](#) .

NQMC Status

This NQMC summary was completed by ECRI Institute on January 6, 2016. The information was not verified by the measure developer.

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Production

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